

Transition: A document written by the Families with Diabetes National Network

Adrienne Burton

The process of transitioning from a paediatric diabetes clinic to adult care is a daunting one for children and young people and their families. There are no standardised, UK-wide recommendations to ensure a seamless transition and make the process as positive an experience as possible. In order to fill this gap, a group of parents from the Families with Diabetes National Network have convened and produced a document outlining what makes a smooth and seamless transition process. In this article, one of the *Transition* document's authors explains its key points and describes the ideal transition process, which would occur over the period between 10 and 25 years of age and can be divided into four discrete stages.

For young people with diabetes, transition involves moving from a paediatric clinic to an adult clinic as smoothly as possible, often via an adolescent clinic. This process should be seamless and as smooth for the young person as can be. However, in many areas in the UK this is not the case; the process is neither seamless nor smooth, and it can be a shock to the system both for young people and for their parents, who can be shut out without any warning or planning. Sometimes at this point, individuals can disappear from the system completely, which is dangerous and can have an adverse effect on their future health.

At the moment there is no national standardised way to achieve a seamless transition, although this is being worked on by various groups. There are, however, pockets of excellent transitioning in England and Wales. During one paediatric diabetes network meeting, transition was the hot topic. As with all things in the NHS, as parents have now learnt, everything takes time to be implemented from idea to fruition; therefore, one parent volunteered to write a

transition document. How hard could it be?!

A small group of parents from around the country volunteered to help and met in a secret Facebook group to discuss their ideas on what a seamless and smooth transition would look like. Some great points arose from these discussions. We were, however, aware that others had also had great ideas before us, and we incorporated these into our document. A few of the parents had seen a presentation by Alex Silverstein (available at: <http://bit.ly/1YrIsxk>). Alex is a young person who had been through this transition period himself and so had a good idea of what would have worked for him and others. The document we ended up with reflects some of his thoughts as well.

In this article, we summarise the key points contained in the *Transition* document.

Ideal age range for transition

We decided that transition should actually begin at an early age, earlier than was probably imagined. We believe transition should start as young as the age of 10 years and not finish until

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Article points

1. The Families with Diabetes National Network have produced a best practice document for transition from paediatric to adult diabetes care.
2. Transition is recommended to begin as early as 10 years of age and, in an ideal world, not end until around age 25 years, to allow young people to finish their education and settle into new careers/lives before being thrust into the world of adult diabetes care.
3. The document also recommends introducing a "capability record" to document the individual knowledge and skills of each young person.
4. Further advice on social media and provision of information and psychological therapy is given.

Key words

- Families with Diabetes National Network
- Transition

Authors

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Page points

1. The process of transition should begin as early as the age of 10 years and not finish until the age of 19 at a minimum; ideally, it should continue until age 25.
2. A “capability record” – an online and printed document listing all of a child or young person’s competencies in managing their diabetes – should be introduced from the day of diagnosis.
3. Social media is a huge part of life for young people and should be encouraged to aid with peer support, although young people should be warned about the risk of misinformation and avoid using it for medical advice.
4. Psychology should also be incorporated in the transition process, and seeing a psychologist should be as typical as seeing a nurse or dietitian.
5. Medical teams also need to provide information on practical aspects of daily life that may be affected by diabetes, such as disability allowance and driving.

the age of 19 years at a minimum. In an ideal world, we believe that 25 years is the best age to finally be transitioned fully into the world of adult diabetes care. This would give young people a chance to finish their education or settle into their new jobs whilst still having the extra support from a young adult centre before being thrust into the world of adult care.

Capability record

We agreed that a “capability record” should be introduced from the day of diabetes diagnosis, no matter the age of the individual. This record then follows the journey from the day of diagnosis to the day the individual enters the adult clinic system. This is a bit like the “red book” documenting children’s health from birth to age 5 years, but it is purely for diabetes and is used for a longer time.

This record needs to be accessible for all and so may need to be available on paper as well as online. It needs to be accessible for the young people, their parents and their diabetes team, and possibly with some parts available for schools and colleges to look at. We originally thought it could be called an “achievement record” but eventually decided on the term “capability record” as we did not want it to be used as a stick to beat young people with over what they could or could not do. The record should, however, include everything that is necessary for young people to look after themselves and build a picture of the individual and his or her current abilities. The wording of the document needs to be suitable for all readers and not just the medical profession. Example items include the following:

- Can you do your own BG finger test safely (BG – blood glucose)? Yes or no?
- Do you know how to read the number on the meter? Yes or no?
- Do you know what is the BG reading for a hypo? Yes or no?
- Do you know what to do to treat your hypo? Yes or no?

The diabetes team, parents and young people can determine what should be ticked and when, perhaps at each clinic. This has to be a partnership between everyone involved. Schools

can access this information if they want to, with the young people/parents’ permission, or the relevant parts can be printed out for schools, further cementing the working partnership between the medical team, family and school.

Social media

In the 21st century, social media is an enormous part of life for young people, including within the context of their diabetes. This needs to be discussed frequently, both at home and in a clinical setting, at all ages from 10 years upwards. It needs to be made clear that, whilst there is a need for peer support and that this is a positive thing, there are some potentially dangerous groups on the internet. If young people are going to join a peer support Facebook group, blog, etc., then it needs to be made clear that not all the help and advice given is correct, and these sites should be used more for support than for obtaining medical advice. The advice is not always positive and can even be dangerous; nonetheless, peer support is necessary for confidence, self-esteem and the feeling of fitting in. Social media should actually be encouraged for this support, especially with teenagers, who sometimes will only ever talk with other teens.

Psychology

Psychology also needs to be incorporated as part of transition. It should be as typical as seeing the paediatric diabetes nurse or dietitian, not just an offer of “would you like to see a psychologist?”. How many young people are going to answer yes to this? A single appointment is not always beneficial, however, and so continuous ongoing meetings with and without the family should be arranged.

Information provision

Medical teams also have a role to play in providing information and practical support for daily life. There is some information that applies to all ages, including information on Disability Living Allowance, Cinema Exhibitors’ Association cards (free cinema entry for a companion) and Carer’s Allowance. In addition, within the transition period there should be readily available information and discussion

about applying for a driving licence and how diabetes can affect driving, and about workplace rights and part-time work: what people with diabetes should be informing employers about, whether they have to tell employers about their diabetes and, indeed, whether it is safer to do so.

The transition journey

Ideally, transition will be a long process occurring over a number of years. In our document, we have divided the process into three, or ideally four, stages. It is important to note that the age ranges are guidelines and are not set for all children/adolescents. The essential requirements for transitional care during these stages are outlined below. The *Transition* document outlines the roles of the young people, families and healthcare professionals in each stage in greater detail.

10–14 years

This is when the voice of the young person needs to be encouraged. They need to become involved in decision-making and they need to be spoken to directly, rather than via the parent. Moving to secondary school is an overwhelming, frightening time through which young people need to be guided. They cannot leave their diabetes at home; it has to go with them. This is where the psychology team can help with ideas of how to tell new friends and generally deal with this time of life.

The young people should be given contact details of someone within the diabetes team to email directly. However, this is not all about the medical team; the parents also have to do their bit, along with the schools.

The idea of moving to an adolescent clinic within the paediatric clinic needs to be introduced. Perhaps this clinic could be at a different time of the week, where there are similarly aged young people in the waiting room rather than lots of younger children.

14–17 years

This is a crucial time of GCSEs and A levels. In addition, young people need to be introduced to the idea of finally moving to an adult clinic. They will need to be told exactly how an adult clinic works and how vastly different it is. They and their

family then need to work out a timetable as to how and when this move will finally take place.

17–19 years

This is where the young people finally move into adult care. Parents should not be cut out of this period, however. While the young people are completely at the forefront now, they still live at home and their parents still help them to an extent, and restricting the parents' knowledge of what their children are meant to be doing is actually a hindrance.

In an ideal world: 19–25 years

We believe there should be a young adult centre up until the age of 25. The brain is still developing up to this point, and at the age of 19 many people are still in education or just finishing, so they are not settled and they are not thinking about the future. The transition to adult care should be about the young people and what is right for them as individuals. Some may well be ready at the age of 19 but others will not. However, this part should absolutely be parent-free except in certain circumstances.

We believe young people need a chance to finish their education or settle into their new careers/lives, which requires the extra support of a young adult centre before that final thrust into the world of adult diabetes. We believe that, this way, they have a lower chance of being lost in the system or dropping out totally.

Concluding remarks

Transitioning from a child-friendly hospital setting to an adult clinic is daunting. At present, there are no standardised, UK-wide recommendations to achieve a seamless transition process. With this in mind, a group of parents from the Families with Diabetes National Network have combined their knowledge and produced a document to outline the key components of a successful transition process. ■

The *Transition* document is available to be shared. It can be downloaded from the National Children and Young People's Diabetes Network website at: <http://bit.ly/1V6vFyj>

Page points

1. Ideally, transition will be a long process occurring over a number of years. It can be divided into three, or ideally four, discrete stages as follows.
2. At 10–14 years of age, children need to start being addressed directly, not through the parents, and to start becoming involved in decision-making. The idea of moving to an adolescent clinic within the paediatric clinic needs to be introduced.
3. At 14–17 years, they need to be briefed on how adult diabetes care will work and plan a timetable as to how and when this move will eventually take place.
4. At 17–19 years, adult care should begin; however, parents should not be entirely shut out of the process.
5. Ideally, the transition process should continue until the age of around 25 years, allowing young people to finish their education or settle into their new careers/lives, which will still require the extra support of a young adult centre. However, this part should absolutely be parent-free except in certain circumstances.